Differential Use of Computer Network Services*

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*Supported by a grant form the National Institute on Aging, AG 8647
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In two randomized field experiments, one involving persons living with AIDS (PWAs) and another involving caregivers of Alzheimer's Disease patients (AD caregivers), we evaluated the ComputerLink, an electronic network designed to support home care. ComputerLink offered a feasible and effective means to reach home-bound individuals. PWAs and AD caregivers demonstrated different patterns of ComputerLink use. Two measures of use are employed: number of encounters with the system and number of accesses to specific functions.PWAs used the system more often than did the AD caregivers, and were more likely than the AD caregivers to use private rather than public communication services.

INTRODUCTION

Computer technology, now a familiar tool to the health care professional, also offers patients and clients powerful assistance managing health care needs and coping with illness. Home-bound patients and informal caregivers represent two important groups who stand to benefit from effective use of computer technology. The needs of the these groups include information to manage health problems, peer and professional support, and skill-building to handle the challenges of home care (Haley et al, 1987).To address the needs of home-bound individuals we developed the ComputerLink, a free, public computer network designed to provide communication, information and decision support (Brennan, Moore and Smyth, 1991; Brennan, 1991). In two field experiments we demonstrated that such a computer network can and will be used by home-bound individuals, and documented some of the effects of use (Brennan et al, 1991).
It is timely to explore the manner in which individuals involved in the ComputerLink experiments actually used the system. Documented to date is evidence of use of single-purpose, free-standing computer technology, for example, computer-aided diet planning (Clark and Ellis, 1982). The ComputerLink projects provide a unique opportunity to examine use of an omnipresent, comprehensive utility, not a single software program. Exploration of these use patterns provides base-line evidence of how patients and caregivers may use a computer network. Comparison of use in two groups provides a basis for describing health services delivery via computers.

BACKGROUND

The ComputerLink, a set of specialized programs and utilities residing within a public computer network, provides home-bound individuals with a pathway to reach peers and professionals, and with access to specialized services. ComputerLink consists of three functions: an electronic encyclopedia (EE) that contains illness-specific information; a communications utility that provides both public (i.e. bulletin board, "Forum") and private (private mail) services, and a decision support system. The decision support system, built on a multi-attribute utility model (von Winterfeldt and Edwards, 1986) employs English-language questions to guide users through a decision analysis. The ComputerLink interface is menu-driven, and the system is available 24-hours a day.

Two groups were selected for the preliminary demonstration and feasibility studies of the ComputerLink. The groups were selected because they represent rapidly growing segments of the home care population: Persons Living with AIDS (PWAs) and caregivers of Alzheimer's Disease patients (AD caregivers). PWAs demonstrate a varied illness trajectory, characterized by

0195-4210/92/$5.00

illness trajectory, characterized by progressive decline in health, and months of home care interspersed with periodic hospitalizations (Lewis, 1988). AD caregivers, once the caregiving role is assumed, provide in-home management, supervision and care of the demented person for periods as long as 15 years.

PWAs and AD caregivers share many similarities in their needs. Both groups are home-bound, as much due to fatigue, time demands, and stigma as to physical restrictions (Lewis, 1988; Stone Cafferata and Sangl, 1987). Their home care needs extend beyond that which are amenable to existing medicine and clinical practice. Both groups have enormous information needs which are unlikely to be satisfied in brief office visits or in standard educational programs. Therefore, it is logical to employ computer technology to meet these needs.

It is also important to note that there are many differences between PWAs and AD caregivers. PWAs suffer from a debilitating illness that has both physical and psychological manifestations, and lack the physical stamina to maintain contact with peers (Lewis, 1988). AD caregivers frequently face multiple role demands, including caring for the demented person and for young children simultaneously (Stone et al, 1987). Traditional health services may not meet the needs of these two groups.

To date only a few computer applications exist for PWAs and none for AD caregivers. The most common applications are computerized bulletin boards and specialized risk assessment program (Bosworth & Gustafson, 1991). Other examples of computer applications directed for patient use include a smoking cessation program (Schneider, Walter, & O'Donnell, 1990) and patient education projects (Clark and Ellis, 1982, 1992). Additional computer-mediated applications, such as computer-aided telephone services (Alemi, Stephens, & Butts, 1992), differ from the applications discussed here because CATI systems use a voice-digital telephone interface and do not take advantage of the range of computer equipment features.

Experimental Protocol

Two ComputerLink systems were constructed, and the two experiments ran in parallel during the period 1989-1991. Details and preliminary findings of these experiments are reported elsewhere (Brennan 1991 & 1992) Both ComputerLink projects followed essentially the same research protocols: randomized field experiments comparing persons receiving standard care with persons who have 24-hour-a-day in home availability of ComputerLink. Participants in both experiments used identical equipment (Wyse 30 terminals with 1200 baud modems). Research nurses delivered computer terminals to the homes, and trained each subject in the use of the ComputerLink.

Both ComputerLinks were constructed in similar manners with the same basic functions (information, communication and decision support). Participants could use the ComputerLink as often as they wished and all costs, including equipment and monthly phone bills, were covered by grant funds.

The two ComputerLink experiments differed in their primary purposes. The PWA ComputerLink targeted the use of ComputerLink for the delivery of nursing services to home-bound PWAs. The specific nursing services delivered via ComputerLink included patient education, therapeutic group process, and interpersonal support. The AD caregivers served to demonstrate the use of ComputerLink to augment self-help and social support services for AD caregivers. The experiments also differed in length; the PWAs participated for 6 months; the AD caregivers participated for 12 months. A separate Electronic Encyclopedia, containing condition-specific information was constructed for each ComputerLink.

SAMPLE

Participants in both studies were recruited through convenience sampling strategies, and were randomly assigned to either the control or experimental conditions. 54 PWAs participated; 25 were randomly assigned to the control group and 29 were assigned to the ComputerLink group; of these 29, 26

completed the six-month study. 102 AD caregivers were recruited; 51 were assigned to the control group and 51 to the experimental group; of these, 47 completed the 12 month study. In both experiments subjects in the control groups did not differ from subjects in the ComputerLink groups in terms of sociodemographic factors or experimental mortality. Data presented addresses only the ComputerLink groups.

Table 1: Persons with AIDS:

Age	33 (s.d. 7.3)
% Male	84%
% White	64%
Years School	13 (s.d.2.6)
% living alone	29%
% Working	35%
% Requiring Assistance	26%

Table 2: AD Caregivers & Patients

	Caregivers
Age	60 (s.d.14.4)
% Male	33%
% White	74%
Months of Caregiving	34 (s.d. 26.8)
% completed High School	84 (86%)

	Patients	
Age		74.8 (s.d. 8.28)
% Male		41%
Relationship to Caregiver	Spouse	67 (68%)
	Daughters or dau-in- law	26 (28%)
	Son	7 (7%)
	Other	8 (8%)

30% of the AD caregivers provided care for someone other than the person with AD(such as a child); most PWAs were responsible for their own care.

Use Data

Data on ComputerLink use were collected from three sources: a passive electronic monitoring record that incremented each time a user accessed a new screen within ComputerLink; the printed text of messages on the Forum, and two focus groups, one conducted at the end of each experiment. In this paper, two measures of "use" are employed: *encounter*, referring to a single log-on, log-off period, and *access*, denoting a subject's use of a ComputerLink function.

RESULTS

The PWA ComputerLink remained active for 325 days (11 Months), permitting all 26 PWA participants to use the system for six calendar months. The AD caregivers' ComputerLink remained active for 19 months, permitting each of the 47 AD caregiver 12 consecutive months of use. There were a total of 8449 encounters on the PWA ComputerLink and 3875 encounters on the AD caregivers ComputerLink.

PWAs accessed the ComputerLink a median of 129 times (mean number of accesses 279). AD caregivers accessed the ComputerLink a mean of 83 times (s.d.101.86). One PWA used ComputerLink over 1300 times; among the AD caregivers a 78 year-old woman made over 500 uses.(In neither group was age correlated, positively or inversely, with number of encounters).The mean length of encounter for participants in both groups was about 13 minutes; most encounters involved access to two or more functions.

Tables 3 and 4 summarize, for PWAs and AD caregivers respectively, accesses to specific ComputerLink functions. All subjects examined each function at least once. Participants in both groups used ComputerLink at all hours of the day, although PWAs were slightly more likely to use ComputerLink between 1AM and 3AM than were AD caregivers.

Table 3
PWA ComputerLink Function Access
(Ss could access > one function per Encounter)

Function	# Function Access
Private Mail	6086
Forum	4326
Electronic Encyclopedia	763
Decision Making	195

Table 4
AD ComputerLink Function Access
(by Encounter)

Function	Total # of Encounters in which Function was Accessed
Forum	3724
Private Mail	1888
E E	518
Decision Making	91

A similarity exists between the two groups of users: communication functions (including the Forum and Private Mail) are used more than information only (EE) or decision support. Decision problems users identified and analyzed with the ComputerLink include choosing a nursing home, consideration of entry into clinical trials research, and planning return to school.

PWAs posted 493 messages to the Forum; AD caregivers posted 622 messages. It is important to note the ratio of postings to Forum accesses for each group: PWA: 493/4326 (i.e. postings on 11% of accesses); AD Caregiviers, 622/3724 (postings on 17% of accesses). Because the Forum received a great amount of attention from both groups, and because it is in the Forum that professional staff interact most often with participants, it is useful to examine the nature of posted messages.

Following modification of a scheme employed by Toseland and Rossiter (1989) to characterize conversations in support groups, messages on the ComputerLink Forum were categorized into one of four themes: general well-being, health related concerns, developmental issues, and group maintenance and support (See Table 5). Developmental issues differed for the two groups: for PWAs relationships with families and lovers predominated; for the AD caregivers, developmental issues included interpersonal concerns, the impact of caregiving, and sources of social support. 17% of the messages posted by the PWAs contained more than one theme and could not be classified in this manner.

Table 5
Themes Found in the Forum Postings

Category	PWAs* n (%)	AD Caregivers n (%)
General Well Being	75 (15)	3 (1)
Illness Concerns	122 (25)	161 (26)
Developmental	127 (25)	224 (36)
Group Maintenance	81 (16)	230 (37)

* 17% classified in more than one area

DISCUSSION

In experimental evaluations of specialized computer networks we found that PWAs used ComputerLink more often, and with greater frequency, than the AD caregivers. Common wisdom erroneously suggests that the difference in number of encounters is explained solely by differences in the ages of the participants in the two groups. It is a long-standing and unsupported myth that computer use is a function of age (Dunkle et al, 1984), with younger persons being more likely to use computer technology than older persons. In these studies, as in others, this myth does not hold .

The preliminary nature of these studies demands caution when exploring what appear to be differences in use behavior. The difference in numbers of encounters may be due to user health status, or simply to the time available to interact with the system. PWAs may have had more time to interact with the system. Manifestations of AIDS, particularly difficulty remaining asleep (Lewis, 1988), may explain the high number of late-night uses by PWAs. AD caregivers noted in the focus groups that it was difficult to find free time to use ComputerLink.

Both groups used communications functions more extensively than any other function. PWAs were more likely to use private mail services; AD caregivers were more likely to use the The Forum. However, the ratio of postings to accesses on the Forum was low for both groups. It is possible that the number of accesses reflects user behavior of checking for mail. It is also possible that users were browsing, or reviewing old messages found to be of help.

This behavior could be characterized as observing, and does parallel behavior seen in other computer networks (T. Grundner, Personal Communication) and that noted in support groups. Almost one-half of the AD caregivers involved in the ComputerLink project reported attending a support group; therefore it is likely that their Forum behavior was similar to face-to-face group behavior.

Important differences between the two groups appear when examining Forum messages. The messages of PWAs focused more on concerns about illness issues; the AD caregivers focused more on group maintenance issues. This difference is understandable, because the users in the PWA group were ill themselves, while the AD caregivers' primary reason for participation was the need for support when caring for another. For both groups developmental concerns emerged as the second most important issue in the Forum.

Similar to other studies of decision support, subjects made few uses of the decision support area; this was unexpected since difficulties with decision making is common to both AD caregivers and to PWAs (Haley, 1987; Lewis, 1988). The approach employed for decision support (decision analysis) may be more difficult for the users than a problem-focused expert advising system . It is also possible that users did not view their decisions as sufficiently important to conduct the analysis. Finally, it is also possible that "discussions" with peers in the Forum or private mail offered decision making assistance in a manner more familiar to the users' preferred modes of interaction.

CONCLUSION

ComputerLink serves as a demonstration that naive users can and will use computer technology for health-related purposes. Health services planned for computer network delivery must consider how the presence of an illness and the time available to use the system may influence potential patient use. Communication services, both public and private, proved to be the most highly used, and potentially most valued, components of computer network services.

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